



This is a repository copy of *Vulnerable subjects and autonomous actors : the right to sexuality education for disabled under-18s*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/150826/>

Version: Accepted Version

Article:

Daly, A., Heah, R. and Liddiard, K. orcid.org/0000-0002-1220-3740 (2019) Vulnerable subjects and autonomous actors : the right to sexuality education for disabled under-18s. *Global Studies of Childhood*, 9 (3). pp. 235-248. ISSN 2043-6106

<https://doi.org/10.1177/2043610619860997>

Daly, A., Heah, R., & Liddiard, K. (2019). Vulnerable subjects and autonomous actors: The right to sexuality education for disabled under-18s. *Global Studies of Childhood*, 9(3), 235–248. © The Authors. <https://doi.org/10.1177/2043610619860997>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Vulnerable subjects and autonomous actors: The right to sexuality education for disabled under-18s

Aoife Daly

School of Law and Social Justice, University of Liverpool, UK

Rachel Heah

School of Law and Social Justice, University of Liverpool, UK

Kirsty Liddiard

School of Education, University of Sheffield, UK

Abstract

International human rights standards are clear that children and young people have a right to sexuality education. Nevertheless the delivery of such education is often considered questionable, particularly for groups of children perceived as more ‘vulnerable’. In this article, the example of the right to access sexuality education for disabled children is used to explore the autonomy/vulnerability dynamic. Historically, sexuality education has been denied to disabled children, ostensibly to protect them from information and activities perceived as inappropriate due to their (perceived) greater vulnerabilities. It is argued however that discourses of sexual vulnerability can actually be dangerous in themselves. Sexuality education, rather than being a threat to disabled under-18s, serves as a way to increase their autonomy by equipping them with tools of knowledge around sex and relationships. This case study demonstrates how the autonomy of under-18s is not something inherent in them, but something which can be enhanced through recognition of rights such as education and information; as well as recognition of adult responsibilities to facilitate this.¹

Keywords

Children’s autonomy; UN Convention on the Rights of the Child; vulnerability; disabled children; sexuality education.

Introduction

Typically, it is assumed that adults are autonomous and that children are vulnerable. In this article, the example of the right to sexuality education for disabled under-18s is used to demonstrate the fluidity of the autonomy/vulnerability divide. ‘Sexuality education’ is understood here broadly to refer to education and information from various arenas on sex, sexuality and relationships. Historically, such education – typically manifesting as a state activity or obligation within the context of formal schooling – has been denied to disabled people generally and disabled under-18s in particular. Perhaps ironically, this has primarily been on the basis that disabled people need ‘protection’ from knowledge of sexuality, and from engagement in sex. It is argued here that, when it comes to sexuality education, there

¹ * Corresponding authors: Aoife Daly and Rachel Heah, School of Law, University of Liverpool, Bedford Street South, Liverpool L69 7ZA, UK. Emails adaly@liverpool.ac.uk; Rachel.Heah@liverpool.ac.uk. Kirsty Liddiard, The School of Education, Edgar Allen House, University of Sheffield, 241 Glossop Road, Sheffield, S10 2GW. Email k.liddiard@sheffield.ac.uk. The authors would like to thank Prof. Helen Stalford, Dr. Jamie-Lee Mooney and the anonymous reviewers for the invaluable feedback which contributed to this article.

tends to be undue focus on children's vulnerability, and a disregard for the potential for autonomy. There is an inclination to err on the side of (ostensibly) 'protecting' under-18s (i.e. excluding them) rather than recognising and facilitating their autonomy rights. Normative, neoliberal adulthood is revered, and it is therefore often unrecognised that disabled under-18s will have intimate lives, and that they will therefore require information and education on sex and relationships.

This article brings together the strands of children's autonomy, disability and sexuality education, providing interdisciplinary analysis through a children's rights framework. It is global in focus, although approached from the perspective of the liberal democracy. We draw upon examples from the UK context in which the researchers are situated to consider the positions and perspectives of disabled under-18s. We are focusing primarily on under-18s, as this is the distinction between childhood and adulthood for most purposes. We are also examining the experiences of this group because so much of the research conducted around disabled people and sexuality is centered around over-18s, and consequently neglects childhood. We are theorising generally about under-18s with disabilities of all kinds, whilst acknowledging the differing experiences amongst this group.

It is argued in this article that discourses of sexual vulnerability can actually be dangerous in themselves. Sexuality education, rather than being a threat to disabled under-18s, is – amongst other things – a way to increase their autonomy rights by equipping them with tools of knowledge around sex and relationships. The fact that sexuality education will likely boost decision-making demonstrates how the autonomy of under-18s is not something inherent in them, but can be enhanced through recognition of rights such as education and information, as well as through recognition of adult responsibilities to facilitate this. It is argued that recent theory emerging from disability studies can challenge the rigid autonomy/vulnerability divide in positive, constructive and transformative ways.

The first section of this article considers the various terms and concepts of agency, autonomy and vulnerability. In the second section, it is highlighted that disabled people, and particularly under-18s, are frequently seen as 'other' in a world prioritising the liberal individual – this applies to perceptions of sexual activities and relationships too. Recent academic theory relating to disabled people and sexuality is considered. The third section involves a closer examination of the nature of sexuality education, and how it is failing disabled under-18s. It is argued that sexuality education is a means of overcoming vulnerability, and that this demonstrates the fluid nature of the autonomy/vulnerability divide. It is also argued that having to consider the rights and interests of disabled under-18s in this context will benefit all humans, by encouraging a rethink of gender and sexual norms.

1. Autonomy, vulnerability and the right to sexuality education

There has been a distinct transformation in the past three decades in how under-18s are viewed in both the social sciences and the legal arena alike. The work emanating from the 'new social studies of childhood' has portrayed under-18s as competent social actors. It has emphasised that under-18s have the capability to influence their environments independently of adults; that they have 'agency' (Oswell, 2013: 3; James and Prout, 1990). This notion of agency perhaps mirrors the 'participation' element to be found in the UN Convention on the Rights of the Child (CRC). There is other terminology which has become ubiquitous when it comes to denoting children's agency – CRC Article 12 refers to children's 'right to be heard'

and to have their views accorded due weight. Daly (2018) argues that ‘autonomy’ is a preferable term in some contexts. The ‘autonomy’ ideal is the norm for many standards in liberal democracies – in social care, for example. The international human rights law framework is based on prioritising the autonomy of the individual in the face of state power (Freeman, 2010: 215).

‘Autonomy’ can mean different things in different contexts. It can be seen as ‘the ideal that we should all have personal freedom in our lives to the extent possible’ (see Daly, 2018: 116). ‘Personal autonomy’ is understood as the individual’s capacity for self-governance. Autonomy can also mean the capacity to make decisions, including the legal right to take those decisions (for example capacity to consent to medical treatment). Yet the word autonomy evokes a relatively clear message – it denotes the desire to determine our own future.

It is crucial to bear in mind that outside of (and perhaps even inherent in) laws upholding it, essentially autonomy is just an ideal. No-one is truly autonomous as our well-being is rooted in our relationships with those around us (Friedman, 2014; Childress, 1990), and we are all constrained in our autonomy by factors such as finances and abilities. This is the case for both adults and under-18s in reality, but nevertheless the law generally assumes that adults are autonomous and that under-18s are not. Standards such as legal minimum ages create and reinforce this situation (see further Daly, 2018). It is assumed that under-18s do not have the cognitive capacity (i.e. abilities relating to knowing, judging and evaluating) to make decisions, though the reality is that under-18s are often capable and adults are often vulnerable (Daly, 2018: 116).

This is perhaps why, in spite of the increasing appreciation for children as autonomous agents, it is the term ‘vulnerability’ that is commonly associated with under-18s as opposed to adults. Children’s vulnerability is regularly cited as a reason why under-18s should not enjoy rights (Herring, 2012). It is also used as justification for a particular ‘protection’ approach to under-18s in law and practice. The heavy protection theme of the CRC reflects the perception in law and in popular discourse of the vulnerability of under-18s, though the term ‘vulnerability’ does not appear explicitly in that instrument. Concern for the perceived vulnerability of under-18s is also to be seen clearly at domestic level – the ‘welfare principle’ in the Children Act 1989 and in the laws of other common law jurisdictions for example ‘is often supported in the name of protecting children’ (Herring, 2012: 43).

In relation to sexual abuse and exploitation, it is inarguable that under-18s are particularly vulnerable. There is, generally speaking, an obvious power imbalance between children and adults, and children therefore must have some element of special protection to account for this. But power imbalance is not exclusively a *children’s* problem. Herring argues that the emphasis on the vulnerability of children ‘is part of an attempt to hide from the vulnerability of adults. It helps bolster the image of the autonomous independent man’ (Herring, 2012: 63). We must, therefore, aim to distinguish between the denial of autonomy where under-18s genuinely need protection on the one hand from unjustifiable paternalism on the other (Daly, 2018).

Increasingly there are calls in academia to recognise our common vulnerabilities as human beings. Fineman (2004: 227) argues that we are all subject to vulnerability in many areas of life (because of advanced age, or global financial crises, for example) and that the focus of law should be on the vulnerable individual rather than the autonomous liberal individual (see

also Tobin, 2015: 157). A failure to recognise vulnerability permits the state to shirk responsibilities, and results in substantive inequalities and the allocation of privilege to the powerful. This is particularly relevant for under-18s – perceived as the opposite of the rational, competent, invulnerable adult. Herring argues that vulnerability need not be seen as an inherently negative thing, instead urging us to embrace it as part of the human condition (Herring, 2016: 1). Fineman urges that greater equality and democracy can be achieved by accepting that we all need support (Fineman, 2008: 19–20).

Vulnerability is a fluid state, of course – factors such as information and education will make a difference. Disabled children are seen as a vulnerable (or perhaps inconvenient) group when it comes to sexuality education and therefore may be excluded from it altogether, rather than being equipped with information tailored to their needs, a point addressed more substantively below. Tisdall opines that understandings of child protection frequently fail to address structural issues, focusing instead on interpersonal relationships such as those between under-18s and exploitative adults (Tisdall, 2017: 60). Similarly the structures surrounding how and whether disabled under-18s can access sexuality education is crucial. Under-18s must be involved in ‘identifying their own concerns and solutions’ (Tisdall, 2017: 60) in sexuality education as in other areas, as considered further in Section 3.

It should be noted that there are of course numerous types of disabilities and these can range from having mild to profound effects on children’s lives. Due to the confines of this article we are being general here. We encompass all disabled under-18s in our central point – that sexuality education, rather than being a threat, is a way to increase autonomy (and therefore decrease vulnerability) by equipping under-18s with tools of knowledge around sex and relationships.

2. Sexual autonomy, youth and intimate citizenship: Constructing vulnerable subjects

Disabled children and young people; viewed as primarily vulnerable?

Sexual autonomy is a powerful ideal in cultures and contexts where ableism and disablism thrive, and where normative neoliberal adulthood is revered (see Liddiard, 2018). Campbell (2009: 44) defines ableism as a ‘network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human’. Ableism is embedded in Western humanist and capitalist values, which demand ability, sanity, rationality, physicality, cognition and autonomy – the universal human defined in the liberal tradition (Fineman, 2008: 10) – as integral to both the human condition and social order (see Braidotti, 2003). Such values denote a compulsory ‘ableness’ (McRuer, 2006: 9): the idea that ‘able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for’. Disablism, however, is the resultant oppressive treatment of disabled people – discrimination, prejudice, exclusion, marginalisation, and a denial of access to multiple areas of private, community and public life and participation in civil society. When we use the term dis/ableism, we are referring to the iterative processes of ableism and disablism, which ‘casts [disabled people] as a diminished state of being human’ (Campbell, 2009: 44).

In dis/ableist cultures, disabled people are routinely denied access to their sexual lives, selves and bodies, across multiple areas of their lives (Liddiard, 2018). As a marginalised group, they experience ‘institutional and legal restrictions on their intimate contact’ (Siebers, 2008: 136). Characteristically refused social and sexual power, agency and autonomy, disabled

people experience an absence of rights to what Plummer (2003) calls intimate citizenship – that which ‘concerns our rights and responsibilities to make personal and private decisions about with whom and how we are in intimate relations’ (Ignagni et al., 2016: 132). In the context of under-18s, intimate citizenship becomes even more difficult to claim, as the impacts of infantilisation, developmentalism, protectionism and desexualisation construct disabled young people as either sexless and/or hypersexual. This binary means that there can be a failure to provide disabled children and young people with the education, information or safe spaces needed to carve out a desired sexual selfhood and identity. There can be an ‘erotophobic approach’ which can lead to hierarchies based on attributes such as age, and physical and mental ability (Wilkerson, 2002: 41). Thus, in the contexts of childhood, youth and disability, sexual and intimate relations are confined and contained according to an ableist imperative that dictates normative desires, practices, behaviours and ways of being (see Liddiard and Slater, 2017). This effectively excludes disabled children and young people ‘from most of the dominant socialisation processes that help teach and prepare people for love, sex and intimacy’ (Davies, 2000: 181).

Historically, sexuality education has been denied to disabled people, as outlined further below. Where sexuality education is offered to disabled young people, it has been criticised by disabled scholars for its focus on normative bodies and normative bodily experiences, which can serve to alienate and further marginalise disabled children and young people, as well as propagate dis/ableist myths such as ‘disability implies asexuality’ (Thompson et al., 2001: 59; see also Davies, 2000; Shakespeare et al., 1996). It is also critiqued for generating raced, cis-gendered, heteronormative and dis/ableist expectations of what it is to be or become adult (Liddiard and Slater, 2017).

Rather than serving to protect, then, discourses of sexual vulnerability ascribed to disabled bodies, minds and selves can materialise as danger in the lives of disabled people. As part of the dis/ableist justification that disabled people are too vulnerable and/or at risk to negotiate the sexual realm, critical knowledges, forms of (accessible) information, and sexual support – as well as the necessary space and access to sexual and intimate life – are habitually disallowed. Paradoxically, this is argued to increase disabled people’s sexual vulnerability, particularly for those with the label of learning disability, disabled women and disabled people who identify as lesbian, gay, bisexual, and/or trans (LGBT) – in effect putting them at a greater risk of sexual abuse and violence (Hollomotz, 2011). Individualist notions of vulnerability exacerbate this problem, placing the onus on the individual rather than ‘the institutional arrangements of domination and subjugation’ (Zavirsek, 2002: 270) that determine disabled people’s bodies as sites of violence. Ironically, the vulnerability label may serve to render disabled children and young people even more vulnerable: putting them at greater risk where they are denied information, education and space to learn and experience.

Troubling the human: Disability and desire

Through disability, however, we may in fact be able to reframe thinking about the intimate lives and knowledge of under-18s. Goodley and Runswick-Cole (2016: 3) argue that disability has ‘the radical potential to trouble the normative, rational, independent, autonomous, subject that is so often imagined when the human is evoked’ – bringing into view a new politics of vulnerability.

Such a position offers the potential to see value in, and the collectivity of, vulnerability; to move from associating it with victimhood and to reclaim it ‘for its potential in describing a

universal, inevitable, enduring aspect of the human condition that must be at the heart of our concept of social and state responsibility' (Fineman, 2008: 8). Vulnerability can instead be an arena for 'human exchange, empowerment, and growth': necessary for human being and human understanding (Rice et al., 2015: 520). It can offer alternative ways of understanding the human subject (Braidotti, 2003) and be embedded in the posthuman condition. This will insist that we consider alternative kinds of citizenship and ways of being human (Liddiard, 2018: 163).

Pulling disability politics into posthuman theory, Goodley et al. (2014: 358) put forward the DisHuman – 'a mode of understanding that simultaneously acknowledges the possibilities offered by disability to trouble, reshape and refashion the human (crip and posthuman ambitions) while at the same time asserting disabled people's humanity (normative and humanistic desires)'. Disabled people are fighting to be recognised as humans, and in the process are engaging in activism and art. This pushes us to think imaginatively and critically about the posthuman (Liddiard, 2018: 163).

Disabled people's exclusion from the category of the Human affects their sexual and intimate lives on a number of levels; compromising their entry into normative sexual categories. It resists their sexual agency and their calls for rights relating to sexuality (Goodley et al., 2015: 11). Yet disability can be a transformative element in normative constructions of sexual ableness, ability and humanness: disabled bodies and minds contest prevalent myths of the sexual body as self-governing autonomous, contained and in control (see Liddiard and Slater, 2017). Disabled bodies quite often require sexual support and assistance in ways that challenge sexual normalcy: 'the (Crip) sexual body emerges as a space of (embodied) relationality and interconnectedness, corporeally interwoven with other bodies and selves in multiple and creative assemblages' (Goodley et al., 2015: 11). Therefore, DisHuman and posthuman modes of thought draw upon 'disability to invoke (emancipatory) posthuman modes of sex/uality which value (and celebrate) inter/dependence; queer; radical relationality, collaboration and collectivity in ways that can be emancipatory for all sexual subjects' (Goodley et al., 2015: 12).

Therefore requiring systems to accommodate sexuality education and information for disabled children will likely have the positive effect of challenging normative constructions of sexuality. This will, in the process, educate teachers, students, policy-makers and others about different experiences, needs and wishes when it comes to relationships, sex and education. It will insist that we think outside the box about what sexual normalcy is.

3. Sexuality education, vulnerability and disabled under-18s

It is necessary to consider what sexuality education is, how it is failing disabled under-18s, and what a transformed approach to sexuality education should involve. Although a detailed proposal for the content of children's rights-based sexuality education for disabled under-18s is beyond the scope of this article, some key components of how to get there – a rights basis; child-lead curricula; and a rethinking of sexuality from the perspective of disability, for example – will be outlined.

Sexuality education for disabled under-18s: Accessibility and content

International human rights standards are clear that children and young people have a right to sex education. The UN Committee on Economic, Social and Cultural Rights is the

implementing body of the International Covenant on Economic, Social and Cultural Rights, which enshrines the right to the highest attainable standard of health (Article 12). The Committee states that Article 12 obliges states to ensure that:

...[U]p-to-date, accurate information on sexual and reproductive health is publicly available and accessible to all individuals, in appropriate languages and formats, and to ensure that all educational institutions incorporate unbiased, scientifically accurate, evidence-based, age-appropriate and comprehensive sexuality education into their required curricula (UN Committee on Economic, Social and Cultural Rights, 2016, para. 63).

The (almost universally ratified) CRC states in Article 17 that children have the right to access information aimed at the promotion of their health, and in Article 24 that states have the obligation to develop preventive health care, education and services. The Committee on the Rights of the Child emphasises that children have the right to “age-appropriate, comprehensive and inclusive sexual and reproductive health education, based on scientific evidence and human rights standards” and that special consideration should be given to disabled children (Committee on the Rights of the Child, 2016, para. 61). States who have signed-up to these instruments have agreed to abide by them. They are, after all, minimum human rights standards. Some countries like the UK (those with ‘dualist’ legal systems) have not yet enacted the necessary domestic legislation which would permit these international treaties to become legally enforceable in courts. However judges do sometimes rely on these international standards in interpreting domestic law (see e.g. *ZH Tanzania v SSHD* [2011] UKSC4). With the advent of children’s rights in the past three decades, it is unsurprising that there is broad international acceptance that sexuality education is a human right. Research shows that sexuality education has become the norm throughout Europe and Central Asia (Federal Centre for Health Education, 2018), which at the very least shows that its importance is broadly recognised at domestic level too.

Much of the problems of implementation of international human rights standards lie in the interpretation of what those standards entail. Neither ‘sexuality’ nor ‘sexuality education’ have specific definitions, but the latter encompasses several components: sex (with a focus on biological characteristics); relationships (with a focus on sexual/romantic relationships and interactions); and sexual health (with a focus on health outcomes and issues relating to sexuality) (Ponzetti, 2015: 26–27). In other words, it goes beyond mere technicalities of sex, to encompass attitudes and feelings (both societal and individual) about the contexts in which sex should happen (Crewe, 2015).

Importantly, sexuality education takes place across a variety of settings – in school, in the family home, amongst friends, on the Internet, television, music, magazines, religious organizations, through personal experiences, and more (Macdowall et al., 2015; Tanton et al., 2015; Ponzetti, 2015). It also takes place across the life-course of the individual, including in school (Ponzetti, 2015), although of course parents, peers and other arenas such as the Internet will be key in the learning of children and young people.

Sexuality education is often denied to under-18s, borne out of a fear ‘that knowledge of sexuality will make them immoral, more sexual, and adult before their time’ (Olsson, 2016: 295). This relates inherently to the idea that under-18s are ‘vulnerable’ and unable to make the ‘right’ decisions in relation to the exercise of their sexuality. Consequently, they should be protected from sexual knowledge until they become ‘capacious’ adults.

If sexuality education is contested for children and young people in general, it is even more problematic in the context of disabled under-18s. The perceived asexual or alternatively hypersexual nature of some disabled under-18s means that sexual activity or expression is often discouraged and prevented by parents, guardians or carers (Travers et al., 2014). It is often assumed that sexual knowledge which opens up possibilities for such activity should also be prevented, ostensibly to protect under-18s from becoming exploited, or from becoming sex offenders (Gomez, 2012; Björnsdóttir et al., 2017). It has been shown that disabled people receive less sexuality education (Björnsdóttir et al., 2017; McDaniels and Fleming, 2016). It has been found that there can be a sense amongst those caring for disabled people that it is ‘someone’s else’s job’ to provide this education, and indeed it has been suggested that a co-ordinated approach from a combination of school, health professionals, and parents is necessary for those with physical disabilities (East and Orchard, 2013). It has been demonstrated that disabled children have less knowledge of sexual matters, such as puberty and safe sex practices compared to non-disabled peers (Galea et al., 2004; Murphy and Young, 2005).

Of course, the right of parents to withdraw their children – to ‘opt out’ – from sexuality education is a prominent matter in the arena of sexuality education. The right for parents to withdraw persists to a large extent, for example in the UK (see e.g. Department of Education, 2018: 7). Although it is a fundamental parental right to determine the nature of their children’s education, it has been argued that it is proportionate to override parental preferences in the instance of sexuality education (Campbell, 2016). In the words of one teacher of disabled under-18s: ‘Our guys can’t opt out of puberty’ (see Williams, 2015). It is likely that parents of disabled children may be particularly worried about the appropriateness of sexuality education. This makes it all the more crucial to insist on framing such education as a means of decreasing vulnerability, as well as providing the tools to form positive relationships.

It is not just the accessibility of sexuality education, but also the content, which fails many disabled children. In her participatory research with disabled young people, Liddiard (2018: 61) found that learning about sex and sexuality is generally done through a lense of dominant expectations of ableist sexual normalcy. These dis/ableist constructions of disability and sex/uality shape the extent to which disabled young people learn about sex and intimate relationships, with the result that disabled people may internalise feelings of otherness. For example here Terry, a 20-year-old man with a disorder involving muscle weakness recalls learning about sex/uality in school. The lesson was focusing on how to put a condom on:

I remember saying – ‘to be fair you’re talking to someone who can’t even open a chocolate wrapper, so I haven’t got much hope, have I?’ I remember it was almost like a shock because he [teacher] said ‘does that mean you’re not going to use contraception?!’ and I said ‘well no, obviously I’d just ask the other person to put the condom on...’ (Liddiard, 2018: 56)

Liddiard states that this indicates that, even in education ostensibly tailored to people with a specific disability, learning can be defined by how disabled people’s experiences deviate from the ableist sexual cultures and practices which are dominant. These kinds of exclusionary approaches can further myths that disability implies asexuality, and education can in fact serve as a means of reproduction of the otherness of disabled people.

Sexuality education as a means of overcoming vulnerability

Sexuality education, rather than being a threat to disabled under-18s is, amongst other things, a way to increase their autonomy rights by equipping them with tools of knowledge around sex and relationships. The UN Special Rapporteur on the Right to Education emphasises that sex education ‘provides the tools that are needed for decision-making in relation to sexuality corresponding to the lifestyle which each human chooses in the context of her situation’ (UN Special Rapporteur on the Right to Education, 2010, para. 17).

Effective, comprehensive and appropriate sexuality education equips children and young people with sufficient knowledge and understanding to navigate the waters of sex and relationships. It facilitates them to exercise autonomy, to make informed choices and to exercise their sexual rights (Crewe, 2015; Galea et al., 2004). It provides them with the language to describe and report incidences of sexual abuse, and breaks down taboos around discussing sexuality which can prevent such reporting (Gomez, 2012). Sexuality education curricula can also address issues like body image, self-identity and self-esteem, which often undermine the confidence of children and young people with disabilities (Gomez, 2012). As such, effective sexuality education is capable of eradicating some of the existing barriers to the exercise of sexual autonomy and expression by people with disabilities, and is a necessity for sexual ‘self-determination and self-advocacy’ (Travers et al., 2014: 233). Although information on positive relationships and on staying safe is obviously relevant for everyone, and for all disabled under-18s, it is particularly important for girls because of the nature of gender relations (see e.g. Campbell, 2016: 1221).

In other words, access to sexuality education is important to reduce sexual vulnerability and promote resilience (Tobin, 2015: 170). It is impossible to eliminate all vulnerabilities and risks inherent in the human condition (Fineman, 2008), yet educating and empowering children and young people to understand and assess risks, and to take action to protect themselves (Shier, 2010: 33), is crucial.

There are clear problems of accessibility and content plaguing ‘traditional’ sexuality education routes for disabled under-18s. There is a need to consider, particularly in a context such as England and Wales, where sexuality education is being re-thought (Heah, 2018), how to carve-out a space for assumptions that, amongst children in all of their diversity, disabled children will be one group who will absolutely need, to some extent at least, a curriculum specific to them. Within this cohort of course, there will be the need to break-down education further in accordance with age and different disabilities. Whilst the Department of Education Guidance on sexuality and relationship education (2018) makes reference to the needs of disabled children it is seriously lacking. The Guidance states that disabled children will require teaching that is differentiated and personalised when it comes to sex and relationships, however there is little detail on how teaching and learning can and should be personalised for pupils within schools (paras 30–32). The Guidance also refers to ‘exceptional circumstances’ in which a disabled child’s special educational needs will be taken into account when making a decision on the parental right to withdraw their child from sexuality and relationship education (para. 44), without giving examples of such circumstances, which runs the risk of disabled children unduly being removed from such lessons.

Forms of delivery outside of school and the family will be crucial. Currently, the Internet is a prominent source of sexual advice and education amongst children and young people, not

least because it is generally affordable, available, anonymous, and private (Barak and Fisher, 2001). Further, an Internet-based model for teaching sexuality education has the potential to be interactive, specific and individualised (Barak and Fisher, 2001: 330). In relation to disabled under-18s in particular, online sexuality education could provide several additional benefits – firstly, in that they would open up access to sexuality education where none such may have existed before, but secondly and more importantly, in that they may allow such education to be tailored to the specific disabilities of the individual. Hence, this could potentially overcome some of the problems arising from the current lack of specificity when it comes to sexuality education for individuals with differing types and degrees of disabilities. More research is required to consider access issues and other specific risks for disabled under-18s. It should not be assumed however that disabled under-18s are more susceptible than others to online risks, or that they have less ability to cope with adverse online experiences (Seale and Chadwick, 2017).

It is not just the content and development of curricula which require attention. A rethink is needed around the extent to which they are resourced, and how to deal with structural discrimination when it arises. This should be approached in a rights framework. The Committee on the Rights of the Child, in emphasising the state obligation to provide sexuality education, state that the necessary human, financial and technical resources should be provided to design and implement such programmes (Committee on the Rights of the Child, 2015, para. 59). Furthermore that instrument recognises state obligations regarding the special needs of disabled children in Article 23. The UN Convention on the Rights of Persons with Disabilities emphasises that states must “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”. At a recent event at the University of Liverpool on sexuality education for disabled under-18s, the issue of resources, and the discretion which schools have concerning how and whether they implement sexuality education was a prominent, perhaps the most prominent theme (see European Children’s Rights Unit Briefing, 2018). This is particularly significant in countries in which dramatic cuts to public services have been enforced, including in the education sector. The knowledge of children and young people about their sexuality should not be dependent on whether schools wish to prioritise it.

There are many ways in which sexuality education could be tailored to account for the needs and common characteristics of groups with particular disabilities. It was found by Schaafsma et al. that, for adults with cognitive impairment interviewed in the Netherlands, the frequency of sex education sessions appeared to be low, as participants did not remember having received sex education. They make the point that it is not just sexuality education, but continuous sexuality education which will be necessary for people with ‘intellectual disabilities’ in order to maintain high levels of knowledge. (2017, 32–33).

It is also important to note that East and Orchard (2013) have found that what literature exists indicates that the majority of sexuality and disability research tends to be focused on sexuality education for youth who have cognitive impairment, while often disregarding the experiences of people with physical disabilities that do not affect their cognitive functioning. They theorise that this is due to a fear of sexual abuse and exploitation of those with cognitive impairment. What this perhaps indicates is heightened attention to the vulnerability of certain subgroups of disabled people, and simultaneously a tendency to neglect the rights and needs of other groups of disabled people when it comes to sexuality education. This highlights the amount of work which needs to be done around adequate attention to different groups. Our own research indicates that the vast majority of the research also focuses on the

education and experiences of disabled adults, rather than on the experiences (or lack thereof) of disabled under-18s. This runs the risk of failing to appreciate the importance of supporting the autonomy of disabled children to understand matters such as power dynamics from an early age.

Of course, CRC Article 12 emphasises that children and young people have participation rights, and it has been examined in detail what this means in the case of education (see e.g. Lundy, 2007). In a similar vein in disability studies and practice the ‘nothing about us without us’ approach is prominent, and it is disabled children and young people who should be developing the curriculum, and even delivering it. Guidance should be taken from good practice examples in sexuality education generally, such as in Norway, Sweden, the Netherlands, and elsewhere, where such education is considered consistent with international guidance and based on the premise that under-18s are rights-holders who have an entitlement to information and to enjoy their sexuality (Campbell, 2016).

There is also much work to be done in countering curricula and attitudes which are contrary to the dignity of disabled under-18s. At the same University of Liverpool event, a number of attendees were teachers providing such education. Some outlined how in their experience disabled children (for example those with behaviour issues) were sometimes excluded from mainstream lessons concerning sexuality education on the basis of presumptions that it was not suitable for them, or that they would be disruptive (see European Children’s Rights Unit Briefing, 2018). Such segregation and inferior education for disabled people is presumably in violation of the UK’s Equality Act 2010. For such discussions to move forward, international human rights frameworks (as well as domestic law equality frameworks) must be harnessed. It must be emphasised through discussion, lobbying and litigation (if necessary) that disabled under-18s have a right to sexuality education, and that an insincere ‘vulnerability’ discourse cannot be instrumentalised by state institutions or others for the purpose of shirking responsibilities.

Conclusion

The exclusion of under-18s from the prioritisation of autonomy in the liberal democracy appears to be based on the assumption that adults’ and children’s worlds, and the experiences inherent in them, are entirely separate (Daly, 2018). Of course they are not – under-18s sometimes engage in sex, are exposed to sexual abuse, and have views and wishes about matters such as medical treatment and family life. Yet the priority for children’s autonomy – whether within relevant laws or popular discourse – does not exist to any degree similar to that pertaining to adults; instead there is generally a binary approach whereby adults are assumed to be autonomous and under-18s are not. Caution is needed in framing autonomy as simply valuing the liberal individual, however. Autonomy must be understood with an appreciation for our relationships with others, and of the fluid nature of our knowledge and capabilities, in that failing to provide support from autonomy may render children vulnerable.

This need to emphasise autonomy, and support for autonomy, is demonstrated well when it comes to sexuality education for disabled under-18s. In dis/ableist cultures, disabled people are routinely denied access to their sexual lives, selves and bodies (Liddiard, 2018). They experience restrictions, both institutional and legal, on their intimate contact (Siebers, 2008: 136). In the context of under-18s, intimate citizenship becomes even more difficult to claim, as disabled under-18s are portrayed as sexless and/or hypersexual. Disabled children and young people may then be excluded from education and other socialisation processes which

prepare people for love and sex (Davies, 2000: 181). Stigmatising ‘vulnerability’ discourses reinforces dominant expectations of ableist sexual normalcy, and cause anxiety for young disabled people (Liddiard, 2018: 61).

Individualist notions of vulnerability place the onus on the disabled child rather than institutional inequality; inequality which features a failure to consider the diversity of the lives of under-18s, and the diversity of those entitled to sexuality education. Such narratives frequently prevent (accessible) information, and sexual support – as well as the necessary space and access to sexual and intimate life – for disabled people. Paradoxically, then, this may increase the sexual vulnerability of disabled under-18s.

Considering the many ways in which under-18s do not fit their mandatory legally incapacitated status prompts us to think about vulnerability. Where under-18s may wish to engage in sexual learning or encounters; where they are themselves parents, for example. Where they engage in behaviours that we do not usually associate with under-18s it becomes clear that the adult/child dichotomy is not so straightforward. It prompts questions as to whether holding adults as entirely responsible, unless they are deemed to entirely lack mental capacity, is sensible: as Herring (2012, 2016) has argued in the context of consent to medical treatment and other matters.

Likewise being compelled to consider what kind of sexuality education is desired, useful and appropriate for disabled under-18s will encourage us to rethink sexuality education itself. It compels us to ask how the content, structure and delivery of sexuality education must be tailored to meet the needs of those who do not fit normative stereotypes. It prompts us to question how it can be delivered without perpetuating and reinforcing inequalities already in existence between adults and children; and between disabled and non-disabled people. It is disabled under-18s themselves who must lead this discussion and lead the design and delivery of sexuality education.

Where systems are compelled to accommodate sexuality education and information for disabled under-18s, it will have a positive effect of challenging normative constructions of sexuality. This will educate populations more generally, as it will insist that we think outside the box about what sexual normalcy is, and about what autonomy and vulnerability really mean in this and other contexts.

References

- Barak A and Fisher W (2001) Toward an internet-driven, theoretically-based, innovative approach to sex education. *Journal of Sex Research* 38(4): 324–332.
- Björnsdóttir K, Stefánsdóttir Á and Stefánsdóttir GV (2017) People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sexuality and Disability* 35(3): 295–311.
- Braidotti, R (2003) Becoming woman: Or sexual difference revisited. *Theory, Culture & Society* 20(3): 43–64.
- Campbell M (2016) The challenges of girls’ right to education: Let’s talk about human rights-based sex education. *The International Journal of Human Rights* 20(8): 1219–1243.

Campbell FK (2009) *Contours of Ableism: Territories, Objects, Disability and Desire*. London: Palgrave Macmillan.

Childress J (1990) The place of autonomy in bioethics. *Hastings Center Report* 20(1): 12–17.

Committee on the Rights of the Child (2015) *Concluding Observations: Ethiopia*. UN Doc. CRC/ C/ETH/CO/4–5.

Crewe M (2015) Between worlds: Releasing sexuality education from bondage. In: Ponzetti JJ Jr (ed) *Evidence-based Approaches to Sexuality Education*. New York and London: Routledge, pp. 122–136.

Daly A (2018) *Children, Autonomy and the Courts: Beyond the Right to be Heard*. Leiden: Brill/Nijoff.

Davies D (2000) Sharing our stories, empowering our lives: Don't dis me! *Sexuality and Disability* 18(3): 179–186.

Department of Education (2018) *Relationships Education, Relationships and Sex Education (RSE) and Health Education: Guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams, teachers*. London: Department of Education.

East L and Orchard T (2013) Somebody else's job: Experiences of sex education among health professionals, parents and adolescents with physical disabilities in Southwestern Ontario. *Sexuality and Disability* 32(3): 335–350.

European Children's Rights Unit Briefing (2018) *Disabled Under-18s: Rights to Online Information/Communication about Sexual Relationships*. European Children's Rights Unit, Liverpool.

Federal Centre for Health Education (2018) *Sexuality Education in Europe and Central Asia: State of the Art and Recent Developments – An Overview of 25 Countries*. Cologne: Federal Centre for Health Education.

Fineman M (2004) *The Autonomy Myth*. New York: The New Press.

Fineman, M (2008) The vulnerable subject: Anchoring equality in the human condition. *Yale Journal of Law & Feminism* 20(1): 1–23.

Freeman M (2010) Upholding the dignity and best interest of children: International law and the corporal punishment of children. *Law and Contemporary Problems* 73(2): 211–251.

Friedman M (2014) Relational autonomy and independence. In: Veltman A and Piper M (eds) *Autonomy, Oppression, and Gender*. Oxford: Oxford University Press, pp. 42–60.

Galea J, Butler J, Iacono T and Leighton D (2004) The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual & Developmental Disability* 29(4): 350–365.

Goodley D and Runswick-Cole K (2016) Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Cultural politics of education* 37(1): 1-15.

Goodley D, Runswick-Cole K and Liddiard K (2016) The DisHuman child. *Discourse: Cultural politics of education* 37(5): 1-15.

Goodley D, Lawthom R., and Runswick-Cole K (2014) Posthuman disability studies. *Subjectivity* 7(4): 342–361.

Gomez MT (2012) The S words: Sexuality, sensuality, sexual expression and people with intellectual disability. *Sexuality and Disability* 30(2): 237–245.

Heah R (2018) Sex education gets a revamp but parents still allowed to opt kids out. *The Conversation* 27 July 2018: <https://news.liverpool.ac.uk/2018/07/27/sex-education-gets-revamp-parents-still-allowed-opt-kids-out/> (accessed 6 August 2018).

Herring J (2012) Vulnerability, children, and the law. *Law and Childhood Studies: Current Legal Issues* 14: 243–263.

Herring J (2016) *Vulnerable Adults and the Law*. Oxford: Oxford University Press.

Hollomotz A (2011) *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London: Jessica Kingsley Publishers.

Ignagni E, Fudge-Schormans A, Liddiard K and Runswick-Cole K (2016) Some people aren't allowed to love: Intimate citizenship in the lives of people labelled with intellectual disabilities. *Disability & Society* 31(1): 131–135.

James A and Prout A (1990) *Constructing and Reconstructing Childhood: New Directions in the Sociological Study of Childhood*. Oxford: Routledge.

Liddiard, K (2018) *The Intimate Lives of Disabled People*. Oxon and New York: Routledge.

Liddiard K and Slater J (2017) 'Like, pissing yourself is not a particularly attractive quality, let's be honest': Learning to contain through youth, adulthood, disability and sexuality. *Sexualities* 21(3): 319–333.

Lundy L (2007) 'Voice' is not enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal* 33(6): 927–942.

Macdowall W, Jones KG and Tanton C (2015) Associations between source of information about sex and sexual health outcomes in Britain: Findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3). *British Medical Journal Open* 5: e007837.

McDaniels B and Fleming A (2016) Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability* 34(2): 215–225.

McRuer R (2006) *Crip Theory: Cultural Signs of Queerness and Disability*. New York and London: New York University Press.

Murphy N and Young PC (2005) Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology* 47(9): 640–644.

Olsson H (2016) Openness and opposition: Sexuality education in Europe. In: Ponzetti JJ Jr (ed) *Evidence-based Approaches to Sexuality Education*. New York and London: Routledge, pp. 292–314.

Oswell D (2013) *The Agency of Children*. Cambridge: Cambridge University Press.

Plummer K (2003) *Intimate Citizenship: Private Decision and Public Dialogues*. Seattle and London: University of Washington Press.

Ponzetti JJ Jr (2015) Sexuality education: Yesterday, today and tomorrow. In: Ponzetti JJ Jr (ed) *Evidence Based Approaches to Sexuality Education*. New York and London: Routledge, pp. 25–38.

Rice C et al. (2015) Project Re•Vision: Disability at the edges of representation. *Disability & Society* 30(4): 513–527.

Schaafsma D, Kok G, Stoffelen JMT and Curfs LMG (2017) People with intellectual disabilities talk about sexuality: Implications for the development of sex education. *Sexuality and Disability* 35(1): 21–38.

Seale J and Chadwick D (2017) How does risk mediate the ability of adolescents and adults with intellectual and developmental disabilities to live a normal life by using the Internet? *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1): 1–16.

Shakespeare T, Gillespie-Sells K and Davies D (1996) *Untold Desires: The Sexual Politics of Disability*. London and New York: Cassell.

Shier H (2010) Children as public actors: Navigating the tensions. *Children & Society* 24(1): 24–37.

Siebers T (2008) *Disability Theory*. USA: University of Michigan Press

Tanton C, Jones KG, Macdowall W et al. (2015) Patterns and trends in sources of information about sex among young people in Britain: Evidence from three National Surveys of Sexual Attitudes and Lifestyles. *British Medical Journal Open* 5: e007834.

Thompson SA, Bryson M and De Castell S (2001) Prospects for identity formation for lesbian, gay, or bisexual persons with developmental disabilities. *International Journal of Disability, Development and Education* 48(1): 53–65.

Tisdall EKM (2017) Conceptualising children and young people's participation: Examining vulnerability, social accountability and co-production. *International Journal of Human Rights* 21(1): 59–75.

Tobin J (2015) Understanding children's rights: A vision beyond vulnerability. *Nordic Journal of International Law* 84(2): 155–182.

Travers J, Tincani M, Whitby PS and Boutot EA (2014) Alignment of sexuality education with self determination for people with significant disabilities: A review of research and future directions. *Education and Training in Autism and Developmental Disabilities* 49(2): 232–247.

UN Committee on Economic, Social and Cultural Rights (2016) General Comment No. 22 on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights) E/C.12/GC/22 (2 May 2016).

UN Committee on the Rights of the Child (2016) General Comment No. 22 on the implementation of the rights of the child during adolescence CRC/C/GC/20 (6 December 2016).

UN Special Rapporteur on the Right to Education (2010) UN Special Rapporteur on the Right to Education, Report to the UN General Assembly (Sex Education) UN Doc. A/65/162. Geneva: UN.

Wilkerson A (2002) Disability, sex radicalism and political agency. *NWSA Journal* 14(3): 33–57.

Williams R (2015) Pupils with learning difficulties are being denied their right to sex education. *The Guardian* 23 March 2015: <https://www.theguardian.com/education/2015/mar/23/learning-difficulties-sex-education-abused> (accessed 6 August 2018).

Zavirsek D (2002) Pictures and silences: Memories of sexual abuse of disabled people. *International Journal of Social Welfare* 11(4): 270–285.